Patients' Experiences of Post-Radiotherapy Skin Reactions

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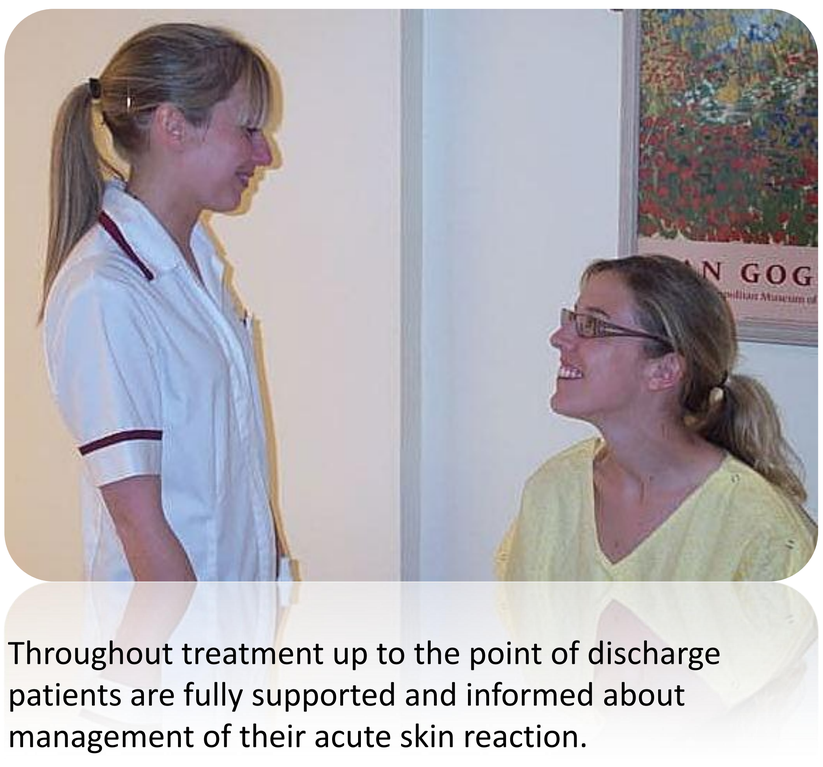
INTRODUCTION

The patient journey within cancer care has an increasing emphasis on enhancing quality of life after completing treatment.

The Scottish Government Cancer Action Plan (2008)[1] stresses that services be patient–centred. In order to improve patients' experiences it is essential to seek their views.

A key challenge has been to develop local communication pathways to ensure all relevant healthcare professionals are aware of skincare guidance and interventions.



Throughout treatment up to the point of discharge patients are fully supported and informed about management of their acute skin reaction.

Cancer Centre staff have highlighted a grey area around the consistent and cohesive care following discharge to the community as advocated by NHSQIS (2004)[2].

*"**Likewise there are patients who leave and have the most horrendous experience but don't make contact, when asked why not they say that they were told to expect it so they just got on with it"*** Pilot Data from Clinicians

This highlights the importance of hearing directly from these health consumers about their experiences.

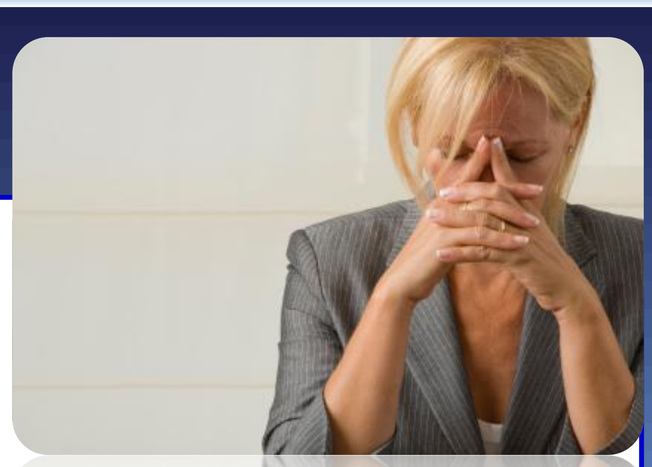
Thus the **aim** of this research –
To explore experiences of patients when discharged to the community, in respect of skin reactions that may develop after radiotherapy.

METHOD

Focus groups and individual interviews, 3-5 weeks after completion of radiotherapy (when skin reactions will have manifested) were undertaken in settings of the participants' choice.

To reduce bias or direction the data generation was facilitated by a health professional who is not a therapeutic radiographer. Thematic analysis was undertaken by two members of the team, and a consensus of meaning developed by team members.

Ethical and R & D permissions were granted by the relevant local NHS committees.
Interim findings are presented on the right



FINDINGS

The end of the journey – restarting normal life

This can be an abrupt unwrapping of the safety blanket of regular communication. Some patients take this as confirmatory of their fitness; others worry about being left so long before further consultation.

"There are lots and lots of questions that have been left unanswered"

Patients empathy with team's obvious pressure of work

Patients realize how busy the staff are, and don't want to bother them with what they perceive as trivial requests for information about skin care. The feel they've used up their portion of time.

"you run out of time too - the appointments are never long enough – never - there's still not enough time to have all those questions answered"

Communication and information

Internet is used as a source of information, but not always acknowledged to the radiotherapy team, as their information is presented as the gold standard. Non conformers may tend to lie low, and keep quiet for feel of confrontation.

"I used to almost feel intimidated if I mentioned the aloe vera thing, because they said I really shouldn't be doing that because there's no research that has proven that this works" " I had to stop telling them what I was doing, I just kept it quiet….I couldn't face the conflict at the end of the week"

DISCUSSION

The majority of skin reactions reported were minimal, suggesting that skin care regimes were undertaken successfully, although there were issues around patients using creams of personal preference.

The feelings of the 'end of the journey' concur with findings from a recent postal questionnaire survey of breast patients[3]. 'After discharge' is indeed identified as a key time from the perspective of cancer patients[4], and this confirms the need for ongoing continuity of care, perhaps providing a linkage between acute services and primary care.

This research suggests that although the service is promoted as patient-centred, from the patients' perspective it appears to be only as patient-centred and individually tailored as finite NHS resources allow. Patients are keen to restart normal life, feeling they have had their share of 'NHS attention', and need to move on. However, they look back to the radiotherapy team as the source of practical information, rather than to the GP team.

With respect to reviewing best practice guidelines, it is suggested that ongoing contact with a therapeutic radiographer may be useful as it appears that patients may feel more able to ask questions of radiotherapists than of doctors[5], and where resources are tight, this confirms there may be great scope for extended therapeutic radiographer/nurse roles. Production of information leaflets[3] could include information on safe information seeking via the internet[6]

REFERENCES
1. Scottish Government. 2008. *Better Cancer Care: An Action Plan.* Edinburgh: Scottish Government
2. NHS Quality Improvement Scotland. 2004 Best Practice Statement Skincare of Patients Receiving Radiotherapy. Edinburgh: NHSQIS
3. McIlroy P, McIntyre A, Ross A, Gallagher C, Brown C (2008) Breast radiotherapy: a single centre survey of non –medical weekly patient review, *Journal of Radiotherapy in Practice,* **7** 19-29
4. Kendal M, Boyd K, Campbell C et al (2006) How do people with cancer wish to be cared for in primary care. Serial discussion groups of patients and careers, *Family Practice*, **23** (6) 644-650
5. Cameron JL, Blyth CM, Kirby AS (2008) An audit of a radiotherapy review clinic for breast cancer patients: a multi-disciplinary approach, *Journal of Radiotherapy in Practice,* **7** 233-239
6. Ellis M, Ellis B (2006) Evaluating World Wide Web-based foot care information, *The Diabetic Foot*, **9** (1) 38-48